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Open Wounds and Healed Scars

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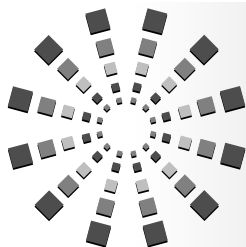
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Open Wounds and Healed Scars

A Qualitative Study of Elderly Women's Experiences With Breast Cancer

KEY WORDS

Breast cancer
 Cancer
 Experiences
 Older patients
 Oncology
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 Qualitative research

Background: Breast cancer is more prevalent among women 60 years or older than among women younger than 60 years. However, we know much more about the breast cancer experiences of younger women than of older women. Such knowledge is important, for example, to guide treatment decisions or to provide psychosocial care. **Objective:** The aim of this study was to gain insight into the experiences of women with breast cancer 70 years or older. **Methods:** Semistructured interviews were conducted with 21 older patients with breast cancer in the Netherlands. We used open coding and affinity diagramming to evoke the themes reflecting the experiences of these women. **Results:** Four themes emerged from the data: living through and coping with breast cancer, information exchange and informed choice, support experiences, and impact on daily life. Getting breast cancer took some women by surprise. However, older women with breast cancer coped fairly well and were satisfied with the support they received, especially from oncology nurses. Disturbing treatment adverse effects and changes in appearance, comorbid diseases, lack of clear information, and/or an unsupportive environment complicated their living with breast cancer. **Conclusions:** Even though many older women with breast cancer handle their disease rather well, some women do encounter difficulties. Lack of

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support, comorbid diseases, and treatment adverse effects warrant extra attention.

Implications for Practice: Nurses' close attention to women at risk and early intervention could help relieve individual suffering, while taking these women's strengths into account can enhance self-management.

Breast cancer is the most common cancer type among women in the Netherlands and worldwide.^{1,2} With increases in both diagnoses and survival, more women will have to deal with breast cancer and its consequences. Although most of these women are 60 years or older when diagnosed,^{2,3} the media tend to portray the average breast cancer patient as a young woman in the prime of life, often with a job and young children.⁴ Obviously, breast cancer can tremendously affect the lives of premenopausal women.^{5,6} Nevertheless, the media attention to young women does not do justice to the problems of older patients with breast cancer. Even in the scientific literature, attention to patients with breast and other cancers seems to diminish with increasing age. The lack of knowledge about the effectiveness of psychosocial interventions in older patients with cancer is characteristic in this respect.⁷

Although women with breast cancer of all ages can experience physical deformities, pain, fatigue, and fear of recurrence, older women may also have age-specific problems and needs regarding breast cancer, diagnosis, and treatment. Comorbidity is a major complicating factor and a cause of undertreatment of older patients.^{8,9} Surgery for older patients increases the risk of postoperative complications because of comorbidity.¹⁰ Age itself strongly influences treatment decisions,¹¹ which has consequences for morbidity and mortality rates. Since 1990, the overall survival of younger patients (<65 years) with metastasized breast cancer in the Netherlands has significantly improved, whereas the survival of older patients has not. This may be due to either undertreatment or overtreatment.¹²

Still, the specific practical and psychosocial factors needing attention in this elderly population may be more important than the medical factors. Many older women with breast cancer must care for an ill family member, often the spouse or a child,^{13,14} or deal with the emotional needs of overwhelmed family members.¹⁵ "Survivor loneliness"¹⁶ can strike women with breast cancer of all ages, but older women who have lost their husbands may be at increased risk of loneliness. Logistical problems can complicate treatment,^{15,17} and general aging characteristics, such as poor vision and hearing loss, cognitive decline, and locomotive problems, hamper communication with health professionals. Personal choice or family preferences, limited social support, concerns about quality of life, or lower life expectancy may all influence the treatment decision and can result in non-optimal treatment.^{8,17} Furthermore, Dutch policy changes have resulted in reduced hospital stays, an increase in the number of outpatient treatments, and a growing need for family members to care for their ill loved ones.^{18,19} This requires higher levels of patient self-management and care coordination and the availability of people willing to fulfill a supportive role.²⁰

Surprisingly, although breast cancer implies a deterioration of well-being and quality of life, it does not automatically lead to

increased suffering in any patient group, young or old. Research results are mixed though. Some studies describe the regularity and persistence of distress symptoms such as anxiety and depression,²¹ especially among younger women with breast cancer,²² whereas others indicate that severe distress is relatively rare in breast cancer survivors, and distress tends to diminish over time.^{23,24} Cancer in general can also positively influence some patients' lives.²⁵ It is important to detect those patients who suffer and cannot deal with their situations and offer them the support they need. At the same time, we may learn from patients who cope well or even perceive benefits as a consequence of their illness (eg, greater appreciation of little things in life or personal growth). Without knowing about the well-being, needs, and wishes of these patients, it is impossible to deliver tailored medical and supportive care. The aim of this qualitative study was to investigate the breast cancer experiences of women 70 years or older and the care they received from healthcare professionals, family members, and other informal carers in their personal network.

■ Methods

We chose a qualitative design as best suited to research relatively unexplored fields²⁶ and to explore and understand complex psychosocial issues.²⁷ Semistructured interviews were conducted with older women with breast cancer living in the northeast Netherlands. All but 1 patient were recruited from 3 community hospitals. The Medical Ethical Committee of Isala Hospital, Zwolle, approved the study (reference no. 12.09110). All participants gave informed consent, and data collection took place from November 2012 to April 2013.

Participants and Procedures

Women 70 years or older at the time of breast cancer diagnosis were eligible for participation in this study. The other inclusion criteria were (a) completion of hospital-based treatment 3 to 24 months before participation, (b) being able to understand and speak Dutch, and (c) being physically and mentally able to converse for an hour. Patients in the palliative phase were excluded. We used systematic, nonprobabilistic sampling to recruit participants.²⁸ Variety in age, education, ethnicity, civil status, and treatment modalities was favored to provide an extensive picture of these women's experiences.²⁹ We used various strategies to enroll participants. Nurses from 3 hospitals searched hospital files for eligible patients and contacted them by phone. They explained the study aims and the research method and asked the patients if they would participate in a 1-hour interview. The Dutch Breast Cancer Society recruited 1 additional participant living in the same area. If a patient was interested, a research team member

contacted the patient again by phone, gave additional information if necessary, and scheduled an appointment. The first author (B.E.) and the research assistants conducted all interviews in the patients' homes. A psychologist (B.E.) and a psychologist-gerontologist (C.S.) extensively trained all the research assistants in interview techniques before they conducted any interviews. The participants were informed that they could withdraw their consent at any time during or after the interview.

Measures

The research team developed a semistructured interview guide including a topic list (Appendix A, Supplemental Digital Content 1, <http://links.lww.com/CN/A14>), which covered the matters of interest and was based on scientific review literature about cancer patients' needs and experiences.^{21,30,31} The interview guide was tested and evaluated after every interview by the research team and the interviewers. The interview covered 5 topics: factual occurrences and reactions, experiences concerning breast cancer care and daily life, social support, knowledge about breast cancer and decision making, and desires concerning possible improvements in breast cancer care.

Data Analysis


The interviews were audio recorded and transcribed verbatim within a few days after the interview. Two analytic methods, conventional content analysis, and affinity diagramming were combined and administered in a 3-step approach. First, after the transcripts were read and reread; a group of 4 researchers (2 psychologists and 2 social gerontologists) independently coded the interviews with inductive content analysis.^{32,33} Every interview was coded by 2 researchers; coders worked in varying pairs. The strength of this analytic method is that the study participants directly provide the information, and the researchers search the data with open minds without any preconceived theories or perspectives.³² Because we realized that researchers always do bring some of their own background into the analytic process,²⁶ the researchers thoroughly discussed each coded transcript with the other coder of that respective interview to ensure rigor. A third coder was consulted if there was a major disagreement. The 4 researchers met on a regular basis to discuss the coding process and the resulting coding list. The second step in the analysis consisted of composing and naming the categories. The research group used affinity diagramming for this step,^{34–36} which involved 2 sessions led by a process leader. All 127 codes were written on cards, and the researchers grouped the codes into categories without speaking to avoid influencing each other's choices and to diminish any possible power differences. Any disagreement about classification was discussed afterward until consensus was reached. Then, the researchers independently named the categories and again discussed their findings. The discussions were recorded. In the third step, we used the same procedure of affinity diagramming to group the 19 categories into themes and to label the themes (Appendix B, Supplemental Digital Content 2, <http://links.lww.com/CN/A15>). Three categories contained factual information about patient demographics and cancer and treatment characteristics. These categories were not combined in a theme. Instead, this information is displayed in the Table.

Results

Twenty-nine older women meeting the inclusion criteria were invited for the interviews. A total of 21 women, between 71 and 89 years of age, agreed to participate and completed their interviews. The Table shows a demographic profile of these 21 participants. One woman declined because she had no time. Another woman thought the interview would be too burdensome. The reasons for nonparticipation of the 5 other women are unknown. One patient declined to participate after initial consent. She had second thoughts about the interview after consulting her daughter.

This was the first time that most of the women were diagnosed as having breast cancer. Apart from 3 women who had been treated for breast cancer twice in their lives, they found themselves on largely unfamiliar ground. The aggressiveness and size of the tumors varied, but almost all the women received a combination of treatments. Some women needed surgery shortly after the first operation because of complications or because the sentinel node had not been removed.

Four themes showed the differences and similarities in these women's experiences: (1) living through and coping with breast

 **Table • Description of 21 Participants in the Study**

Characteristic	n	%
Age, y		
Mean	77.1	
SD	5.72	
Marital status		
Married	9	42.8
Divorced	3	14.3
Single	1	4.8
Widow	8	38.1
Children		
Yes	16	76.2
No	5	23.8
Grandchildren		
Yes	15	71.4
No	6	28.6
Living situation/housing		
Single-family home	11	52.4
Apartment	4	19.0
Sheltered housing	5	23.8
Nursing home	1	4.8
Vocational level		
Low-skill jobs	12	57.1
Medium-skill jobs	4	19.0
High-skill jobs	1	4.8
Never had a paid job	3	14.3
Level unknown	1	4.8
Treatment modality (>1 method is possible)		
Lumpectomy	10	47.6
Mastectomy	14	66.7
Radiation therapy	13	61.9
Chemotherapy	4	19.0
Hormonal therapy	10	47.6

cancer, (2) information exchange and informed choice, (3) support experiences, and (4) impact on daily life.

Theme 1: Living Through and Coping With Breast Cancer

This theme represents the experiences of these women with having breast cancer and their health in general, their emotions, and their coping mechanisms. Some women spoke about the medical characteristics of their tumors, but they spoke much more about their hospital experiences and treatment consequences. Approximately one-third stated that they had had little inconvenience during or after treatment. For example:

It was miraculous how well everything went. Really incredible!!! I never had any pain. I was not nauseous after the operation. Absolutely nothing. (C1)

Not everyone came out unscathed, however. Fatigue, nausea, fluid retention, a thick or stiff arm, inflammation, open wound, and lack of appetite were the most common adverse effects. One woman's lungs were damaged during radiation, and 1 woman developed thrombosis due to hormonal therapy. The cosmetic consequences were very disturbing to some women. Weight loss, baldness due to chemotherapy, and mastectomy resulting in ugly scars or loose pieces of breast were especially disquieting. This woman was very shocked when she saw the result of the removal of her breast:

It looks bad, it looks bad. I told the surgeon, this does not look right.... It is, I had expected everything, but not this. I'll show you if you want. (C19)

She was offered a breast reconstruction but refused because of her age. Even though she said that she was getting used to it, a large part of the interview was about this subject that still made her emotional.

However, it was not only the breast cancer that could cause these women trouble. Other ailments and comorbid illnesses such as cardiovascular and lung diseases, rheumatism, and osteoporosis were much more debilitating to some and influenced the way they looked at their breast cancer and treatment.

I am disabled [by severe back problems]. I need my arms, and if I am left [after the breast operation] with an arm that no longer functions, they can drag me to the nursing home. (C3)

The possible treatment adverse effects could be frightening, but despite the physical limitations that many women encountered, they showed a mentality of stolidness and vigor. Several women also had an accepting and positive attitude that helped them cope. Sometimes they compared their situations with those of younger women with breast cancer or with patients with different types of cancer in their environment who, in their views, were worse off.

But I prefer older people getting it than younger women, those who are at the start of life. If they have to lose a breast, I think that is worse. (C9)

The women had many other ways of dealing with their situations and with feelings of shock, anxiety, sadness, or anger.

Some examples are brooding, working it out by themselves, lighting a cigarette, becoming less active, or turning to others for support. In contrast, some women were very explicit about managing by themselves—out of necessity, or just because they valued their independence, or both.

Yes, everything just went on (silence). Yes, yes, I am alone, and I take care of myself; I will do everything by myself, as long as I can; I want to keep on doing that, yes (smiles). (C13)

Theme 2: Information Exchange and Informed Choice

Having breast cancer involves receiving and providing information about the illness, treatment options, adverse effects, support groups, and so on. However, unless the women had worked as medical professionals themselves or knew other women with breast cancer, they were largely unfamiliar with breast cancer and its treatment before diagnosis. The fact that they still could get breast cancer at their age or despite living a healthy life came unexpectedly to some women.

I have always been healthy, so it came as a surprise. ...Can you still get it if you are so old? (C11)

After diagnosis, most women wanted information and appreciated a clear statement from the doctor. Some women were satisfied with the amount of information that was provided; others felt that information about what they could expect was lacking. They contacted the hospital or extensively searched the Internet for information about their disease and treatment options. However, whereas these active information seekers wanted as much information as they could get, others did not read the information provided. Sometimes they got tired of all the information.

Well, they show all these statistics. And what they say about it, yes, yes, we do not know precisely how it works. So, I left that for what it was. (C8)

Understanding and finding the right kind of information was one thing; making treatment decisions was something else. Just as the women reacted differently to their breast cancer diagnoses, their way of making treatment decisions differed. Information about tumor characteristics, treatment options, and adverse effects was important, but not by definition decisive. Stories from other women with breast cancer, family preferences, age at diagnosis, comorbid diseases, and residential situations all could influence their decisions. Still, decision making was always a process between doctor and patient, in which several women had an accepting attitude toward their doctor's advice and did not want or feel they had to make a choice.

Everything was decided in a single day. Yes, it is not good, and then it has to be removed. Yes, you do not, we [husband and patient] did not have to think about that. (C11)

Nevertheless, there were women who doubted the proposed treatment, and some made their own opinions quite clear because they were afraid of the consequences of a certain intervention or because they knew someone who had undergone the same treatment. This woman had made her decision before she

knew the seriousness of her diagnosis and without any discussion with her husband and children.

And then she [doctor] said, well, you can still have a breast-saving operation. And then I immediately replied, no, my breast will have to be removed right away. (C15)

She expected to be finished with her breast cancer treatment after a mastectomy and was unhappy that she still needed chemotherapy.

In some instances, doctor and patient came to a mutual agreement. Straightforward clarification of the treatment options and risks was valued as very helpful in this respect.

Theme 3: Support Experiences

The women generally appreciated contact with and support from healthcare professionals, family members, and acquaintances concerning their breast cancer. Many received and enjoyed support from family members, neighbors, friends, people from the church, and so on. Most women's children strongly supported them. Practical support (such as transportation to the hospital and shopping) was common, and they received many postcards and visitors. However, not everyone wanted to talk about her experiences with her acquaintances, and for some, emotional involvement with family members seemed to be limited.

My daughters know it, but they never ask how I am doing. And still, every afternoon we drink coffee together.... But what do I have to tell them? I take those pills, and they work fine, and as long as I do not have any more symptoms.... (C9)

Some women felt greatly supported by their faith; it was as if "someone" [God] went with them to the hospital, and it was someone they could not have done without during difficult times in the breast cancer trajectory. Apart from the support they received, several women cared for family members themselves. This could be burdensome, but it was not always experienced as such. Some women did enjoy taking care of others, and it meant something to them, whether it was taking an interest in grandchildren or giving practical support to others.

I have a handicapped brother who lives in this village. ...I take care of his payments and all of that. If something needs to be arranged, I will do it. I don't have any problems with that. (C15)

Concerning the healthcare professionals, the oncology nurses were perceived as very supportive. Without exception, all the women were enthusiastic about the nurses. They had more time to explain things than the doctors had, paid attention to psychosocial matters, and were easily accessible.

I could always call a nurse; I had 2 telephone numbers, and if anything happened, I could always call. If you have any doubts whether to call or not, just do it! Just do it! (C21)

This is in line with the overall opinion of the hospital care, which was rated positively. Only 1 woman preferred the care in a smaller hospital because she felt treated like a number when she went to a larger hospital for radiation therapy. A warm environment was important to these women. In general, they perceived the care from medical specialists as professional, although

some had negative experiences with their primary physicians, such as the woman with problems contacting her doctor when she became ill, and he did not order the medication as promised.

When he came round again on Wednesday, I said, well, I was kind of angry with him I think. If he treats me like that again, I'll show him the door. I won't go on with him. I could not talk to him. (C10)

Although during their stay in the hospital, some women enjoyed talking to other patients with breast cancer, they had little wish for actively contacting fellow patients. Only a few went to an organized activity for patients with breast cancer: swimming or a creative afternoon. During these activities, the subject came up only sparsely. Some women explicitly stated that they did not want to talk about their problems with a group of strangers and were therefore averse to this kind of support.

Theme 4: Impact on Daily Life

Breast cancer and its treatment both negatively and positively influenced practical, spiritual, and relational aspects of the women's daily lives or did not have much impact. Many of the women's reflections on this theme were related to practical adjustments, such as the acquisition of a prosthesis or the arrangement of daily transport to the hospital for radiation therapy. For some, these adjustments were troublesome; for others, it was quite easy to make these arrangements, possibly with the help of family members or friends. Help from a friendly shop assistant when getting a prosthesis was greatly appreciated. Several community services provided taxi transport to the hospital for women without any other means of transportation. Those women who had not heard about transportation options regretted it. Overall, the women tried to continue their life as it was before the diagnosis as soon as possible, and they seemed to succeed.

Yes, my condition has deteriorated a bit. But on the other hand, the things I can do again, well, quite a lot, I think. (C7)

Many women tried to maintain a physically active lifestyle, and it seemed they did not want to resign themselves to "taking it easy." However, if their functioning had seriously diminished because of fatigue, nausea, arm problems, and other treatment adverse effects (described in theme 1), they were forced to limit their daily activities to a lesser or greater extent. Still, for some, having breast cancer had a positive impact on their lives.

Yes, I keep on living, but I am much happier now, much. I live more, eh, I do have a lot of fun with people. But even if I read the newspaper, I cut out all the fun stuff. It's silly; I stick it in my diary. (C14)

Finally, breast cancer did not specifically seem to change much in the interaction patterns between patients and their husbands. In general, illnesses of 1 or both partners influenced their daily lives. Some women had lost their husbands very recently and had to cope with this loss during their illness trajectories. A husband with Alzheimer disease or other severe illness was an extra challenge for women who had to deal with their own breast cancer and comorbid diseases themselves. Many women were active informal carers (described in theme 3).

Therefore, the impact of breast cancer on daily life was related to the support that was received from or provided to others in their personal network, but was also related to their mind-set and behavior.

■ Discussion

This is one of the first investigations into the breast cancer experiences of women 70 years or older. It provides a rich description of the lives and care experiences of older Dutch women with breast cancer in 4 themes: “living through and coping with breast cancer,” “information exchange and informed choice,” “support experiences,” and “impact on daily life.” Generally, most older women coped reasonably well. However, negative experiences in almost every theme could impede their well-being and quality of life.

Most of the women had extensive treatment, including surgery, although according to the literature, older women risk being undertreated.^{11,37,38} They are less likely to receive surgical treatment, but if they do, it more often consists of radical mastectomy than lumpectomy.^{9,11,37,38} This correlates with our participants, most of whom received a mastectomy, even though this may have been preceded by a lumpectomy.

The first theme, “living through and coping with breast cancer,” showed diverse experiences and coping mechanisms. Some stated that they were fortunate because everything went well; others had treatment adverse effects such as lymphedema, fatigue, and other problems, which have been summarized elsewhere.³⁹ Physical deformities were not always properly attended to. This may be due to misconceptions about the importance of body image to older patients⁴⁰ or ageism on the part of professionals.^{41,42} Nonetheless, breast reconstruction, for example, can be a safe option for older women.⁴³ Concerning appearance, just like younger women, older women may greatly care about their looks, a fact that is not always acknowledged by their doctors.

Apart from the consequences of the breast cancer treatment, comorbid diseases may be very disturbing and can influence overall survival and distant recurrence-free period.⁴⁴ It can be difficult for older women to correctly attribute their problems to cancer, other illnesses, or aging.^{25,45} A geriatric assessment is recommended to enlighten this abstruseness.⁴⁶ It includes the physical, cognitive, social, and psychological state of the patient. If patients' treatment goals, preferences, and values are also incorporated, decision making is greatly facilitated.⁴⁷

Even though many women were shocked, anxious, sad, or angry at a diagnosis of breast cancer, their mentality, which is supposedly typical of those in the northern Netherlands, may have been helpful to them: stolid, vigorous, and sometimes a little restrained about expressing emotions. This can partially explain the persistence of some women in wanting to manage on their own. Comparing their situations with younger patients who were supposedly worse off may contribute to constructing a “positive story.”⁴⁸ This “downward comparison” has been shown to be an effective coping mechanism to enhance self-esteem.⁴⁹ Furthermore, among the variety of coping mechanisms these

women discussed, active coping styles, such as seeking social support, are the most valued by older cancer patients.⁵⁰

The second theme, “information exchange and informed choice,” shows the importance of tailored information and care. Patients differ in the amount of information they want and can gather by themselves. Overall, it is important that the information is easy to use and is discussed with a healthcare professional.¹⁴ Oncology nurses had more time to explain treatment consequences and psychosocial issues than doctors, which the patients appreciated. Although personalized care is encouraged for patients of all ages, a holistic and personalized assessment of needs becomes even more important with age, especially if there are high levels of comorbidity.⁵¹ Some older women relied on the doctor's opinion, but others had clear preferences about being treated or not. In general, physician recommendation is a very important determinant in older patients' decision making.⁵² Here, too, oncology nurses can have an important role in the sometimes very complicated decision making of older patients in which personal preferences and context have to be checked against treatment benefits and risks.⁵³

Most needs reported in the “support experiences” theme were attended to by family members and friends. The oncology nurses also played an important role in offering psychosocial support. Overall, the hospital care and the medical specialist care were rated positively, excepting some negative comments regarding general practitioners. Women without partners and children may have more difficulty finding support. However, partners were not always considered supportive. As other research reports, the relationship with a spouse did not change much because of cancer,⁴⁸ but may warrant attention if it is disharmonious. Other relatives, friends, and acquaintances did play a valuable role for some of our participants. Some amount of psychosocial support is essential for the patients' well-being,⁵⁴ and such support is a buffer against loneliness, which seems to increase with time.⁵⁵ Being a breast cancer survivor can inflict loneliness, but women tend to search for meaning and cognitively master their experiences.⁴⁹ Some patients felt greatly supported by their faith, although women in more religious countries may rely even more on this form of coping.^{56,57} Providing support to others can also influence the quality of patients' lives and may even reduce mortality risk.⁵⁸ Women with breast cancer, both young and old, have a wish to care for others.⁵⁹

The “impact on daily life” varied. Several women had to limit their daily activities, whereas others were driven to remain active, and some even described very positive changes due to having breast cancer. Those reporting limitations in their daily lives ascribed them to fatigue, nausea, arm problems, and fluid retention. They tended to make the best of their situations and showed their strength and vitality by carrying on their activities as best as they could. Comorbid diseases, taking care of a chronically ill partner, or bereavement could have as much impact on daily life as breast cancer did. The quality of their lives was influenced by many factors, of which breast cancer was only one.

Our findings should be interpreted in the light of some limitations. One limitation concerns the selection. Nurses selected prospective participants from the hospital files. This may

have caused some selection bias if the nurses selected only the most “suitable” patients for the interviews. However, the nurses were told that the patients they selected had to match the inclusion criteria and that we aimed at diversity with respect to demographic variables. The selected women lived in relatively rural areas in the northeast Netherlands. They were white and generally middle class. The sample therefore does not represent the overall Dutch population. Nevertheless, diversity of age, education/job level, civil status, living conditions, and treatment modality was achieved and contributed to a rich description of the experiences of older women with breast cancer. Because of the cross-sectional data registration, we do not know how the future lives of these women will be affected. Including patients who had completed their treatment in the hospital 3 to 24 months previously created a risk of memory distortion. However, we were interested in both experiences during treatment and the long-term consequences of breast cancer.

Younger and older women have many experiences in common regarding breast cancer.⁵⁹ Unlike their younger counterparts, older women usually do not have to deal with job demands, taking care of a young family, and fertility issues.^{5,60} However, their breast cancer trajectories have their own dynamics, with perhaps as much diversity within the older group as between older and younger women. Our focus was not on the young-old controversy. Rather, we want to stress the importance of increased focus on older patients because this is still a relatively unexplored and expanding group. Older women can be ignorant of the risk of breast cancer or may be greatly affected by their changing appearance. Comorbid diseases may be more troublesome than breast cancer, and a supportive environment seems to be crucially important. Still, despite a difficult and life-threatening illness with potential setbacks, these older women seem very capable of coping with breast cancer.

■ Implications

Many older patients with breast cancer are far from deactivated, especially the ones who receive social support and are resilient.⁶¹ For some, the scars will heal easily; for others, breast cancer and its treatment leave open wounds. Our research suggests that women without support and those with complicated health states or adverse effects may be at risk of not receiving the care they need. More attention should be paid to women who need secondary surgery or who want breast reconstruction after mastectomy. Physical appearance can still be significant for older women and needs sufficient attention. It is important to realize that these women will probably not complain often, even if their resilience is put to the test. Accessibility and a warm hospital environment can be very helpful and are greatly appreciated. A friendly word, availability, or genuine interest can make a big difference in the perceived quality of care. Clear information provision and gathering seem to be essential elements in decision making. Some women are strong enough to carry on by themselves with little support from their personal networks, and some women take care of others. Optimal care means incorporating these women's strengths in addition to

investigating their wishes and offering information and options to enhance their self-image if it has been damaged. Nurses are already offering valuable support, but it may be worth intensifying their efforts and drawing their attention to patients in need. The interest among our respondents in support groups was low. These older women seemed reluctant to discuss their problems with fellow patients and probably because of the availability of the nurses had less need to. The wish for peer support may be different in other countries. We note that these women received almost all their breast cancer care from the hospital, and they can approach the nurses until years after active treatment have ended. For other ailments, the general practitioner is the first contact. However, the role of the general practitioner in breast cancer care and care coordination is unclear, and the women were not always satisfied with that role. More research on this subject is needed. The experiences described here provide indications for women who need additional care in 1 or more domains. This will be investigated in a quantitative survey. Finally, our results are based on a subgroup of older women in the Netherlands. Extending this kind of research to women from different cultures and countries is recommended. Older women may share many experiences, but every culture brings along its own dynamics concerning cancer care.

■ Conclusion

Even though Dutch medical care is high-quality care, increasing health costs and the aging of society put more and more pressure on patients' self-management skills and on their informal carers. This creates a risk of overburdening both patients and carers. It is therefore important to search for those aspects warranting improvement. Careful investigation of the patient's needs at an early stage can distinguish at-risk patients from patients who will probably do well on their own or with a little help from their friends and family. Offering additional psychosocial care only to patients in need may relieve individual suffering and limit problems afterward.

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